

Records

Pediatric Kidney-Pancreas Transplant Recipient Follow-Up Worksheet

FORM APPROVED: O.M.B. NO. 0915-0157 Expiration Date: 02/29/2012

Note: These worksheets are provided to function as a guide to what data will be required in the online TIEDI[®] application. Currently in the worksheet, a red asterisk is displayed by fields that are required, independent of what other data may be provided. Based on data provided through the online TIEDI[®] application, additional fields that are dependent on responses provided in these required fields may become required as well. However, since those fields are not required in every case, they are not marked with a red asterisk.

Recipient Information	
Name:	DOB:
SSN:	Gender:
HIC:	Tx Date:
Previous Follow-Up:	Previous Px Stat Date:
Transplant Discharge Date:	<input type="text"/>
State of Permanent Residence: *	<input type="text"/>
Zip Code: *	<input type="text"/> - <input type="text"/>

Provider Information	
Recipient Center:	
Followup Center:	
Physician Name: *	<input type="text"/>
NPI#: *	<input type="text"/>
Follow-up Care Provided By: *	<input type="radio"/> Transplant Center <input type="radio"/> Non Transplant Center Specialty Physician <input type="radio"/> Primary Care Physician <input type="radio"/> Other Specify
Specify:	<input type="text"/>

Donor Information
UNOS Donor ID #:
Donor Type:

Patient Status	
Date: Last Seen, Retransplanted or Death *	<input type="text"/>
Patient Status: *	<input type="radio"/> LIVING <input type="radio"/> DEAD

RETRANSPLANTED

If Retransplanted, choose organ(s):

Kidney Pancreas Kidney/Pancreas

Primary Cause of Death:

Specify:

Contributory Cause of Death:

Specify:

Contributory Cause of Death:

Specify:

Hospitalizations:

Has the patient been hospitalized since the last patient status date: *

YES NO UNK

Number of Hospitalizations:

ST=

Noncompliance:

Was there evidence of noncompliance with immunosuppression medication during this follow-up period that compromised the patient's recovery:

YES NO UNK

Functional Status: *

Cognitive Development: *

- Definite Cognitive delay/impairment
- Probable Cognitive delay/impairment
- Questionable Cognitive delay/impairment
- No Cognitive delay/impairment
- Not Assessed

Motor Development: *

- Definite Motor delay/impairment
- Probable Motor delay/impairment
- Questionable Motor delay/impairment
- No Motor delay/impairment
- Not Assessed

Academic Progress: *

- Within One Grade Level of Peers
- Delayed Grade Level
- Special Education
- Not Applicable < 5 years old/ High School graduate or GED
- Status Unknown

Academic Activity Level: *

- Full academic load
- Reduced academic load
- Unable to participate in academics due to disease or condition
- Not Applicable < 5 years old/ High School graduate or GED
- Status Unknown

Primary Insurance at Follow-up: *

Specify:

Clinical Information

Date of Measurement:

Height: *

 ft. in. cm ST=

Weight: *

 lbs. kg ST=

BMI:

kg/m²

Urine Protein Found By Any Method:

- YES NO UNK

Kidney Graft Status: *

- Functioning Failed

If death is indicated for the recipient, and the death was a result of some other factor unrelated to graft failure, select Functioning.

Kidney Date of Failure:

Kidney Primary Cause of Graft Failure:

Specify

Contributory causes of graft failure:

Kidney Acute Rejection

- YES NO UNK

Kidney Chronic Rejection

- YES NO UNK

Kidney Graft Thrombosis YES NO UNK

Kidney Infection YES NO UNK

Urological Complications YES NO UNK

Patient Noncompliance YES NO UNK

Recurrent Disease: YES NO UNK

BK (Polyoma) Virus YES NO UNK

Kidney Other Contributory Cause of Graft Failure

If Functioning, Most Recent Serum Creatinine: mg/dl ST=

Dialysis Since Last Follow-Up: NO
 YES, RESUMED MAINTENANCE DIALYSIS
 YES, NO MAINTENANCE RESUMPTION
 YES, MAINTENANCE RESUMPTION UNKNOWN
 UNKNOWN

Date Maintenance Dialysis Resumed:

Select a Dialysis Provider:

Provider #:

Provider Name:

Pancreas Graft Status: * Functioning Partial Function Failed

If death is indicated for the recipient, and the death was a result of some other factor unrelated to graft failure, select Functioning.

Method of blood sugar control: Insulin
 Oral medication
 Diet
 No Treatment

Date insulin/medication resumed:

Pancreas Date of Failure

Pancreas Graft Removed: YES NO UNK

Date Pancreas Removed:

Pancreas Primary Causes of Graft Failure

Specify:

Contributory causes of graft failure:

Pancreas Graft/Vascular Thrombosis YES NO UNK

Pancreas Infection YES NO UNK

Pancreas Bleeding YES NO UNK

Anastomotic Leak YES NO UNK

Pancreas Rejection: Acute YES NO UNK

Pancreas Chronic Rejection YES NO UNK

Biopsy Proven Isletitis YES NO UNK

Pancreatitis YES NO UNK

Patient Noncompliance YES NO UNK

Other, Specify:

Conv. From Bladder to Enteric Drain Performed: YES NO UNK

Enteric Drain Date:

Serum Amylase: u/L ST=

Pancreas Transplant Complications (Not leading to graft failure):

Pancreatitis YES NO UNK

Anastomotic Leak YES NO UNK

Abcess or Local Infection YES NO UNK

Other, Specify:

Did patient have any kidney acute rejection episodes during the follow-up period:

- Yes, at least one episode treated with anti-rejection agent
- Yes, none treated with additional anti-rejection agent
- No
- Unknown

Was biopsy done to confirm acute rejection:

- Biopsy not done
- Yes, rejection confirmed
- Yes, rejection not confirmed
- Unknown

Did patient have any pancreas acute rejection episodes during the follow-up period:

- Yes, at least one episode treated with anti-rejection agent
- Yes, none treated with additional anti-rejection agent
- No
- Unknown

Was biopsy done to confirm acute rejection:

- Biopsy not done
- Yes, rejection confirmed
- Yes, rejection not confirmed
- Unknown

Viral Detection:

CMV IgG:

- Positive
- Negative
- Not Done
- UNK/Cannot Disclose

CMV IgM:

- Positive
- Negative
- Not Done
- UNK/Cannot Disclose

Is growth hormone therapy used during this followup period:*

- YES
- NO
- UNK

Post Transplant Malignancy:*

YES NO UNK

Donor Related:

YES NO UNK

Recurrence of Pre-Tx Tumor:

YES NO UNK

De Novo Solid Tumor:

YES NO UNK

De Novo Lymphoproliferative disease and Lymphoma:

YES NO UNK

Bone Disease:

Fracture in the past year (or since last follow-up):*

YES NO UNK

Specify Location and number of fractures:*

Spine-compression fracture: # of fractures:

Extremity: # of fractures:

Other: # of fractures:

AVN (avascular necrosis):*

YES NO UNK

Treatment

Biological or Anti-viral therapy:

YES NO Unknown/Cannot disclose

Acyclovir (Zovirax)

Cytogam (CMV)

Gamimune

Gammagard

Ganciclovir (Cytovene)

Valgancyclovir (Valcyte)

HBIG (Hepatitis B Immune Globulin)

Flu Vaccine (Influenza Virus)

Lamivudine (Epivir) (for treatment of Hepatitis B)

Valacyclovir (Valtrex)

Other, Specify

If Yes, check all that apply:

Specify:*

Specify:

Treatment for BK (polyoma) virus:

YES NO

Yes, Immunosuppression reduction

Yes, Cidofovir

If Yes, check all that apply:

Yes, IVIG

Yes, Type Unknown

Yes, Other, Specify

Specify: *

Other therapies:

YES NO

Photopheresis

If Yes, check all that apply:

Plasmapheresis

Total Lymphoid Irradiation (TLI)

Immunosuppressive Information

Previous Validated Maintenance Follow-Up Medications:

Previous Validated Maintenance Follow-Up Medications:

Were any medications given during the follow-up period for maintenance:

Yes, same as validated TRR form

Yes, same as previous validated report

Yes, but different than previous validated report

None given

Did the physician discontinue all maintenance immunosuppressive medications:

YES NO

Did the patient participate in any clinical research protocol for immunosuppressive medications:

YES NO

Specify: *

Immunosuppressive Medications

[View Immunosuppressive Medications](#)

Definitions Of Immunosuppressive Follow-Up Medications

For each of the immunosuppressant medications listed, check **Previous Maintenance (Prev Maint)**, **Current Maintenance (Curr Maint)** or **Anti-rejection (AR)** to indicate all medications that were prescribed for the recipient during this follow-up period, and for what reason. If a medication was not given, leave the associated box(es) blank.

Previous Maintenance (Prev Maint) includes all immunosuppressive medications given during the report period, which covers the period from the last clinic visit to the current clinic visit, *for varying periods of time which may be either long-term or intermediate term with a tapering of the dosage until the drug is either eliminated or replaced by another long-term maintenance drug* (example: Prednisone, Cyclosporine, Tacrolimus, Mycophenolate Mofetil, Azathioprine, or Rapamycin). This does not include any immunosuppressive medications given to treat rejection episodes.

Current Maintenance (Curr Maint) includes all immunosuppressive medications given at the current clinic visit to begin in the next report *for varying periods of time which may be either long-term or intermediate term with a tapering of the dosage until the drug is either eliminated or replaced by another long-term maintenance drug* (example: Prednisone, Cyclosporine, Tacrolimus, Mycophenolate Mofetil, Azathioprine, or Rapamycin). This does not include any immunosuppressive medications given to treat rejection episodes.

Anti-rejection (AR) immunosuppression includes all immunosuppressive medications given for the purpose of treating an acute rejection episode since the last clinic visit (example: Methylprednisolone, Atgam, OKT3, or Thymoglobulin). When switching maintenance drugs (example: from Tacrolimus to Cyclosporine; or from Mycophenolate Mofetil to Azathioprine) because of rejection, the drugs should not be listed under AR immunosuppression, but should be listed under maintenance immunosuppression.

Note: The Anti-rejection field refers to any anti-rejection medications since the last clinic visit, not just at the time of the current clinic visit.

If an immunosuppressive medication other than those listed is being administered (e.g., new monoclonal antibodies), select Previous Maint, or Current Maint, or AR next to Other Immunosuppressive Medication field, and enter the full name of the medication in the space provided. **Do not list non-immunosuppressive medications.**

	Prev Maint	Curr Maint	AR
Steroids (Prednisone, Methylprednisolone, Solumedrol, Medrol, Decadron)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Atgam (ATG)	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
OKT3 (Orthoclone, Muromonab)	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Thymoglobulin	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Simulect - Basiliximab	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Zenapax - Daclizumab	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Azathioprine (AZA, Imuran)	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
EON (Generic Cyclosporine)	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Gengraf (Abbott Cyclosporine)	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Other generic Cyclosporine, specify brand: <input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Neoral (CyA-NOF)	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Sandimmune (Cyclosporine A)	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
CellCept (Mycophenolate Mofetil; MMF)	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Generic MMF (Generic CellCept)	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Prograf (Tacrolimus, FK506)	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Generic Tacrolimus (Generic Prograf)	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

Advagraf (Tacrolimus Extended or Modified Release)	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Nulojix (Belatacept)	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Sirolimus (RAPA, Rapamycin, Rapamune)	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Myfortic (Mycophenolate Sodium)	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

Other Immunosuppressive Medications			
	Prev Maint	Curr Maint	AR
Campath - Alemtuzumab (anti-CD52)	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Cyclophosphamide (Cytoxan)	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Leflunomide (LFL, Arava)	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Methotrexate (Folex, PFS, Mexate-AQ, Rheumatrex)	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Other Immunosuppressive Medication, Specify <input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Rituximab	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Investigational Immunosuppressive Medications			
	Prev Maint	Curr Maint	AR
Zortress (Everolimus)	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Other Immunosuppressive Medication, Specify <input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>